CHAPTER 9: SURVEILLANCE, RESEARCH AND EVALUATION

This Chapter summarizes on-going HIV surveillance and research activities and program evaluation efforts, how surveillance and research information are linked to the strategies in the plan, and recommendations for additional surveillance and research needed to enhance HIV prevention planning and evaluation in South Carolina.

1. Surveillance

Tracking the Epidemic

The Introduction section of Chapter 1 "Epidemiologic Profile" contains a detailed description of HIV/AIDS surveillance systems in South Carolina. DHEC carefully monitors the status of HIV/AIDS and other sexually transmitted diseases enabling providers to implement strategies in communities around the state based on our best understanding of the epidemic.

In order to monitor the HIV epidemic in South Carolina, state law requires physicians, hospitals, laboratories, and other health facilities to report diagnosed HIV infection and AIDS cases to DHEC. The information includes risk factors, age, sex, race and geographic location. Follow-up with persons diagnosed with syphilis and HIV infection is conducted by health department staff to provide partner notification, confidential testing and counseling services, treatment, and referral to medical and support services. Surveillance data are also used to plan and design prevention and care programs to target persons most at risk for sexually transmitted diseases and HIV infection.

Active surveillance activities include routine visits with hospitals and infectious disease physicians to identify cases and compete CDC case report forms; comparisons with other data sources such as death certificates, TB registry, syphilis registry, and the AIDS Drug Assistance Program.

To evaluate completeness of reporting, surveillance staff periodically obtain the South Carolina Hospital Discharge Summary data and match with the HIV data base. The matching done in 2001 indicated 98% of inpatient and outpatient clients discharged in 1999 with an HIV related diagnosis had been reported. Review of the 2% of cases not initially reported indicated reasons for cases not reported included being out of state cases (therefore assigned to their state of residence not South Carolina), not a true HIV diagnosis, miscoded diagnoses, and insufficient information.

The CDC-funded Supplemental HIV/AIDS Surveillance (SHAS) project obtains sociodemographic, health care, sex and substance use behaviors, and reproductive health information on newly diagnosed persons with HIV infection in five counties (urban and rural areas). Trained interviewers collect information using a standardized instrument.

In an effort to obtain more complete risk information on HIV/AIDS cases, staff completed a CDC-funded Evaluation of Risk Assessment Project in 2000/2001. Staff

reviewed several types of records to determine which records were most useful in obtaining risk information. Records included Partner Notification Interview records, SHAS, …. (John B.)

South Carolina also receives CDC funds for the Enhanced Pediatric Surveillance project that analyzes medical record and other data to evaluate the effectiveness of perinatal HIV prevention efforts. Staff analyze the proportion of HIV infected pregnant women who have knowledge of their serostatus prior to delivery, proportion of HIV infected women prescribed antiretroviral therapy during pregnancy, labor and delivery and neonatal period, proportion of HIV infected women receiving cesarean sections, and selected birth outcomes. Each case of pediatric HIV infection due to perinatal transmission is analyzed to determine which prevention step was missed in order to identify follow-up training, education, or protocol development to ensure no missed opportunity for prevention.

Surveillance staff analyze and disseminate HIV (and other STD's) surveillance data to multiple care and prevention providers, media, community organizations, and others. Surveillance data was used extensively to develop the Epi Profile; data files are produced for local HIV prevention collaborations for local planning efforts; data by Ryan White service area is produced for care planning. Staff produce semi-annual reports which are distributed to hundreds of professionals, and is available on the agency's website. Additionally, numerous custom reports are produced for legislators, local agencies, media, and others for grant writing, policy decisions, state health publications, progress reports and program planning and evaluation efforts.

Linkage of Surveillance Data to HIV Prevention Programming

As mentioned above, surveillance data were used extensively by the CPG to determine priority populations, unmet needs, describe risk behaviors, and evaluate specific prevention efforts. These data are reflected through out this prevention plan.

In addition, surveillance data are used to determine prevention and care funding allocations to local health districts, HIV prevention collaborations, and HIV care consortia.

One of the goals of a prevention system is to reach people who may have no knowledge of their risk of HIV infection. A key strategy to reach people is partner counseling and referral (PCRS). Surveillance data are essential to initiate partner counseling and referral services in South Carolina. All newly reported cases are provided to local disease intervention specialist staff for follow-up partner counseling services. Newly reported persons are contacted confidentially and referred for counseling and voluntary partner identification. Named or identified sex and needle-sharing partners are contacted and referred for HIV counseling and testing services.

Many persons contacted, particularly women, have no awareness of their past or current HIV risk or that of their partner. Because they do not perceive their risk, they are unlikely to actively seek information on HIV or get tested. For many persons, the partner

counseling and referral process is essential for them to learn of their risk and steps to reduce it, and to learn their HIV status. Counseling and testing data indicate that partners of HIV infected persons consistently have the highest positivity rates, indicating the effectiveness of PCRS in targeting at-risk individuals. Referrals to medical care, support groups, substance use treatment, prevention case management, community-based organizations are provided to clients at the time of PCRS.

Surveillance data, particularly HIV and syphilis are also used to identify counties and areas of highest rates that are used to identify locations for the mobile van screening services.

Finally, pediatric surveillance data on HIV–exposed infants is used by local case managers to refer mothers/infants to the Title IV children's care system, and to monitor if subsequent testing has been done for final HIV status determination. (About 25% of HIV exposed infants will become infected without proper treatment; with treatment the risk drops to 8%. Most infants' true HIV status can be determined by 18 months of age.)

Additional Surveillance Needs

The community planning group and STD/HIV health department staff have identified gaps in surveillance information that, if available, would improve the planning process, delivery of interventions, and evaluation of overall prevention efforts. To address these gaps, two primary needs have been identified. First is the need for increased behavioral risk information for the following:

- For reported HIV/AIDS cases with "no identified risk" (NIR)
- For uninfected members of priority populations, e.g. MSM, at-risk heterosexuals, IDU's
- For reported syphilis cases
- For persons receiving targeted HIV/STD screening

For HIV infected cases reported with no risks (NIR's), there is a need to create a mechanism to better characterize heterosexual transmission cases and reduce high number of "no identified risk" category; e.g. count multiple sex partners, other substance use (crack/cocaine), etc. as "Presumed Heterosexual" vs no identified risk.

For persons at risk for HIV, there is a need for additional behavioral risk and social network information necessary to identify high-risk populations, particularly MSM and substance users. While some information is available through existing surveillance data, more complete information to include location of where partners meet, location of high risk behaviors, etc. collected in a more systematic manner would be essential to identify high risk populations (particularly African American MSM) and to identify community sites where interventions need to be targeted.

Second, is the need for HIV prevalence estimates among priority populations and subpopulations by conducting periodic HIV testing among defined populations in clinic and community settings.

A review of the recently updated epi-profile indicates an apparent decline in new HIV cases among injecting drug users and white MSM. It is not known if this is truly declining prevalence/incidence or a reflection of a decline in testing among these populations. Implementing sentinel surveillance activities to obtain estimates of HIV prevalence among these and all priority populations would provide more accurate prevalence data. Additionally, sentinel surveillance activities, that include risk behavior surveillance, will provide baseline and on-going data to assess the effectiveness of overall prevention efforts for each priority population.

2. Research

Learning More About Our Populations and Program Effectiveness

Research in this Plan is defined as activities to acquire information and knowledge to provide further insights and descriptions of systems, provider and population needs which is used to guide planning and programming for more effective HIV prevention services. Research is not defined here as scientific research to determine cause-effect relationships.

During the next three years, three broad areas for research are listed below with key questions. These questions reflect the needs identified by the CPG, DHEC and prevention providers as a result of completing priority setting and needs assessments for this Plan. It is expected that CDC/NIH demonstration project results, literature reviews, and enhanced surveillance efforts, needs assessments and evaluation efforts in South Carolina will focus on answering these questions.

1. Intervention Effectiveness Research

- What interventions are most effective in changing HIV risk behaviors?
- How does intervention effectiveness vary in terms of race/ethnicity, sexual orientation, age and other diversity?

2. Research on the HIV Epidemic in South Carolina

- What is the estimated prevalence of HIV infection among our priority populations?
- How would we implement studies to obtain prevalence data?
- What is the estimated prevalence of risk behaviors among our priority populations?
- What are the core behavioral surveillance data essential for understanding the HIV epidemic in South Carolina?

- Which identifiable subpopulations within MSM, at-risk heterosexual, and IDU populations are most at risk of becoming infected with HIV and should be targeted with prevention interventions?

- How would we implement a behavioral surveillance system to capture useful data?

- How is the overall rate of HIV infection changing? How does this vary by race/ethnicity, age, sex and county of residence?

3. Research on HIV Prevention Programming in South Carolina

- According to our priority populations, what are the best mechanisms to reach and attract them to our services?

- What are the social networks of our priority populations and in what locations do they interact?

- What are the locations of high –risk behavior and how would we conduct our services at or near these locations?

- According to our priority populations, what assets or strengths do they have to support prevention efforts in their communities?

- According to our priority populations, what life circumstances have led them to HIV infection?

- What proportion of our priority populations have been reached by specific interventions?

- What proportion of our priority populations have been referred and successfully linked to other primary and secondary prevention services?

- What are the technical assistance/training needs of our prevention providers?

- How effective is our comprehensive prevention system in impacting changes in knowledge, behaviors and HIV transmission?

- How would we develop an outcome monitoring system to evaluate the effectiveness of prevention interventions on our populations?

3. Evaluation

The research questions listed above will be used to guide the development of the state's HIV prevention evaluation plan for the next three years. An evaluation plan should be realistic, feasible, and take into account the unique needs, resources, capabilities, and priorities of the state health department as well as local HIV prevention providers. The goal is to create a plan that will guide the collection of data for improving HIV prevention efforts and informing stakeholders of the progress made in HIV prevention.

a. Why Do We Need To Create An Evaluation Plan?

Because of the complexity and broad scope of HIV prevention programs, creating an evaluation plan can assist the State health department, CPG and local HIV prevention providers in determining their evaluation needs and setting a realistic and concrete course for meeting them. Table 9.1 outlines some benefits to each of the stakeholders involved in evaluation.

Table 9.1 BENEFITS OF HIV PREVENTION EVALUATION

Community & Provider Benefits	Health Department Benefits	Federal Benefits
• Ensures the quality of service delivery. • Ensures that HIV prevention resources are successfully reaching target populations. • Guides resource allocation. • Documents progress of programs. • Improves programs. • Identifies programs that are effective or ineffective. • Enables the application of findings, which enhances credibility and increases community support. • Increases motivation among staff and volunteers. • Increases the likelihood CBOs will be viewed. positively by private and public funders.	• Fulfills federal reporting expectations. • Describes the status of HIV prevention activities statewide. • Provides the health department with quantifiable documentation of HIV prevention service delivery. • Assists HIV Prevention Planning Groups in assessing statewide patterns of service provision. • Documents the need for HIV prevention services to the state legislature and Governor. • Documents the need for HIV prevention services to the CDC. • Guides resource allocation. • Ensures that funds are being used as intended.	• Fulfills reporting requirements to federal policymakers. • Assist CDC project officers in providing necessary technical assistance to health departments. • Improves policies regarding HIV prevention program implementation.

Two basic evaluation questions that are essential to address in South Carolina's evaluation plan are:

- Did we do what we said we were going to do? (process evaluation)
- What difference did we make in the lives of our participants? (outcome evaluation)

These two questions can be looked at in several ways:

- Formative evaluation: evaluation during the planning and implementation of program activities
- Summative evaluation: evaluation done after program activities are complete.

Data should be collected so that it is meaningful through process and outcome monitoring and feedback, review and program improvement.

Monitoring for process measures addresses:

- What did we do?
- How many people did we do it for?
- How can we improve what we did next time?

Outcome monitoring addresses:

- What changes occurred in individuals as a result of what we did?

Ensuring the quality of the data collected should be emphasized. During the gap analysis it was recognized that collaborations and other community-based organizations are not consistently using a comparable standard to report interventions. Some collaborations are reporting the number of discrete interventions; others are reporting numbers of sessions. For example, a group level intervention, such as Be Proud Be Responsible, that has six sessions is reported as six interventions by one group if it is held at six different times, and as one intervention by others. Given that not all HIV prevention providers are recording data uniformly, it is not accurate to compare data across providers in South Carolina.

b. What Evaluation Activities Are Being Done in South Carolina?

1. Formative Evaluation

Formative evaluation is conducted by prevention providers during the planning and designing of interventions to assess target population needs and to "test" the intervention and identify problem areas or weaknesses before full implementation. Examples of methods prevention providers use include interviews and focus groups with members of target populations to better understand risk behaviors and how best to help them to lower risk, pilot tests of intervention activities, pre-testing materials with target populations to ensure clarity, cultural competency, and input from target populations to discuss best ways to recruit and present information.

All contracted providers (HIV prevention collaborations) and local health department staff conducting health education risk reduction activities must conduct formative evaluation processes. Beginning 2002, these providers must provide summary of formative evaluation processes in their reports to DHEC.

2. Process Monitoring/Process Evaluation

Process monitoring is the collection of data to describe and assess intervention implementation including characteristics of people served and the services provided. Typical process measures include number of clients by an intervention, demographic characteristics (age, race/ethnicity, risk), number of condoms provided, number of outreach contacts made, or number of referrals made to specific services. This information allows state and local staff to monitor program operations to allow refinements; documents that services were given to those priority populations intended to reach, and enables programs to demonstrate accountability and cost efficiency to funding agencies.

All contracted providers (HIV prevention collaborations) and local health department staff must conduct process evaluation. Several systems have been in place to monitor the implementation of programs in South Carolina. Below is a summary description by each program component.

(1). *Counseling, Testing, and Referral Services* demographic data is collected by utilizing the SC DHEC HIV Serology Request Form. Data on individuals tested in local health departments and contracted collaborations are keyed into a computer file at the Bureau of Laboratories and confidentially stored. The DHEC Laboratory provides all HIV testing for the STD/HIV program. The STD/HIV program has developed an out-put report which provides the data required for the CDC counseling and testing reports. Data on pre-test and post-test counseling and referrals are maintained in clinic records and a Patient Automated Tracking System (PATS). Local data are transmitted to a state data base from which counseling reports are performed.

(2). *Partner Counseling and Referral Services* information is collected utilizing the CDC Interview Record form. All forms are sent to the STD/HIV program on a monthly basis and entered in an Epi-Info database and the HIV/AIDS Reporting System (HARS) for data maintenance and reporting.

(3) *Health Education/Risk Reduction Services* are primarily provided by AIDS Health Educators (AHEDS) in the 13 public health districts and the 11 HIV Prevention Collaborations. Both monitor and track their activities previously by using a monitoring/tracking system created on Microsoft Access, detailed activity and services provided logs. These activities are then reported quarterly to the STD/HIV Division.

Starting in the Fall 2001, monitoring on implementation of the interventions will occur by using the CODES , Collaboration and District Evaluation System. CODES is a web-

based system that requests information on the organization conducting the intervention, target population, type of interventions, race/gender/age demographics of population served, materials used, and other collaborating organizations. DHEC will convene a workgroup of providers to develop clear definitions of interventions and target populations and provide training for all providers to utilize. This new system will allow for a systematic and standardized way for all providers to collect and report data. This information will be used to generate reports using Chrstal Reports. Summarized information will be provided to CDC using the ERAS, Evaluation Reporting and Analysis System. The information will also be used by state and local providers to evaluate and improve services.

(4). *Public Information* data is collected in two ways. The DHEC AIDS Hotline staff utilizes a computerized Q & A system to capture information from all callers that are responded to by a staff person. Some calls are received after hours and a message directs the caller to the CDC National AIDS Hotline and indicates the hours of operation if the caller wishes to call back and receive information, counseling, and referral. An analysis of the data collected through Q&A is completed using Epi-Info. Only those calls responded to are analyzed. Data collected includes demographics, risk information if provided, type of information requested, and referral source, e.g. directory assistance listing, radio PSA, etc.

Public information activities provided by local collaborations/district staff are reported through the CODES reporting system described above.

(5). *Capacity Building, training, and technical assistance* data is captured using logs and computer processing software (Word Perfect 6.0). A database is maintained that lists each training event, number of participants, organization/affiliation of participants. Pre/post training assessments used are maintained by the individual trainers.

3. Outcome Monitoring

Outcome monitoring is the on-going measurement of the effects of an intervention on client outcomes like knowledge, attitudes, beliefs, and behaviors. For example, HIV prevention collaboration X is conducting an on-going series of workshops targeting men and wants to see if they are increasing participants' intentions to use condoms. To measure this outcome, the collaboration would administer a survey to participants before and after the workshop, which asks about intentions to use condoms. The collaboration would compare participants' answers to assess change in intentions due to the HIV prevention workshop.

CDC does not require HIV prevention providers to conduct outcome monitoring at present but encourages states that have the capacity to develop outcome monitoring. South Carolina has not developed or required prevention providers to formally implement outcome monitoring. However, based on the recommendations for research in this Plan, input from local providers and desires of policy-makers and funders in South Carolina, DHEC will be developing an outcome monitoring process during the next three years to

determine the statewide effectiveness of selected prevention programs. This process is described in DHEC's Evaluation Plan for 2002 – 2004 submitted with the 2002 HIV prevention cooperative agreement application. CDC evaluation funds will be used to support this effort as well as existing state and local staff support.

DHEC and local Ryan White care providers have recently developed an outcome monitoring/evaluation plan to determine the impact of care services. This process utilized a committee of key stakeholders and followed the United Way Model process "Measuring Program Outcomes: A Practical Approach".

Similar to the HIV care model, the emphasis for prevention outcome monitoring will be to develop a select number of practical, feasible outcomes and indicators and select existing or design essential data systems to measure indicators. The CPG recommends that the outcome evaluation/monitoring committee utilize the key research questions in this Plan as a framework for selecting prevention outcomes.

In the short term, some local prevention providers may begin implementing outcome monitoring as resources allow. To assist, DHEC will provide example questionnaires, data collection tools to measure pre/post impact. Feedback from those providers who initiate this type of evaluation will be useful and important for the development of a statewide system as described above.

4. Outcome Evaluation

For the purpose of HIV prevention, CDC defines outcome evaluation as the measurement of outcomes such as knowledge, attitudes, beliefs, and behaviors in persons receiving interventions and the comparison of changes in interventions participants to similar person who did not receive the intervention (comparison or control group). Using the workshop example in outcome monitoring above, a group not receiving the workshop intervention (comparison group) perhaps in another county, would complete the same surveys at similar time intervals as the workshop group. Changes in the workshop participants' answers would be compared to changes in the comparison group's answers to see if changes were due to the HIV-prevention workshop. Note the primary difference from outcome monitoring here is that this evaluation method is more "rigorous" requiring comparison groups.

South Carolina is required to conduct an outcome evaluation with a selected intervention or set of integrated interventions. CDC recently revised the guidance for states required to conduct outcome evaluation. The new guidelines allow states to conduct outcome monitoring for specific interventions as an alternative to the more rigorous outcome evaluation process. DHEC's evaluation plan incorporates the outcome monitoring approach.

Designing and Evaluating Intervention Plans

A key component of the evaluation activities described above is the development and review of local implementation plans. The purpose of evaluating intervention plans is to determine each intervention's soundness and feasibility and to assess its correspondence to the comprehensive HIV prevention plan.

AIDS Health Educators (AHEDS) in the local health districts and contractors for the HIV Prevention Collaborations are required to submit Local Implementation Plans that reflect priorities in the State HIV Prevention Plan. In Local health department staff were required to develop Operational Plans. DHEC will be developing a system for measuring the outcomes of their activities.

The collaboration contractors are required to complete intervention planning forms for each of the intervention types they will conduct during the year. The intervention planning form is a web-based form and mirrors the process evaluation data they will be required to collect. The intervention planning form requires the contractor to indicate who is being targeted (indicating risk behavior, race/ethnicity, age, and gender), type of intervention, scientific basis of the intervention, and a detailed description of the steps in carrying out the intervention. The web-based system for planning interventions may be viewed at: www.dhec.gov/dhecapps.codes.

Staff in the STD/HIV Division review these plans and provide feedback regarding target populations and interventions.

c. Recommendations for Enhancing Our HIV Prevention Evaluation Efforts

When addressing outcome issues, South Carolina should be looking at behavioral indicators rather than at infection rates. Prevention providers should, at a minimum, begin to identify indicators, collect baseline data for priority populations that can be used to evaluate intervention effectiveness.

We must also look at ways to determine if we are making a difference in communities, if what we are doing is reaching them. The questions of research on HIV prevention programming in South Carolina (listed on pages 4 and 5) are likely to be addressed through qualitative data collection. These questions address:

- Reaching priority populations;
- Social networks of priority populations;
- Where these populations live, how they live, their strengths and assets, their life circumstances;
- What interventions reach priority populations;
- The referral process to other primary and/or secondary interventions;
- Technical assistance needs of prevention providers;
- The efficacy of our prevention system.

We need to look at improving qualitative data collection and developing better methods to collect and analyze the data. Areas of focus include collaboration among service providers, demonstrating community involvement and resident participation in each project or program, demonstrating community awareness before and after interventions, and finding better ways to build validity and reliability into evaluation methods.

At the systems level, we identified the need for:

- The CPG, DHEC, the collaborations and other CBOs to agree on the scope of evaluation;
- Broadening evaluation, and inviting participation of those who are implementing programs in the community.
- Listening to stories of community members, considering their context and finding better ways to document what we hear;
- Recommendations for increasing relevance and utility of evaluations and the potential for learning at the level of program implementation, as opposed to evaluation as a punitive process that measures inadequacy
- The need for a cultural competence framework so that community action and change can be appropriately documented, analyzed and reported
- Understanding the culture of community based organizations and encouraging community based evaluation perspectives that are contextually meaningful
- Continued emphasis on evaluation throughout program activities so that evaluation becomes an accepted and integral component of program planning.

Key Recommendations for Surveillance, Research and Evaluation:

Improve and increase availability of behavioral risk information and develop mechanisms to estimate prevalence of HIV among priority populations through sentinel surveillance models.

Ensure that the community planning needs assessment process and prevention interventions address the framework of questions listed.

Ensure standardized and consistent data collection and reporting of process evaluation data to improve quality of data for resource inventory and gap analysis during 2002 – 2004.

Develop feasible, practical statewide outcome monitoring process to measure impact of prevention programs on priority populations.